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## Level of discordance between adolescents with lupus & their providers

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The importance of incorporating patients' subjective assessment of their disease status into assessment/treatment plans as a means to improve patient compliance and communication with providers has been increasingly reported in the literature. This study evaluated the level of discordance between adolescent lupus patients' perceptions of the overall disease activity and their providers' rating of disease activity. A secondary data analysis was done of 861 lupus patients (ages 12-23 years) using data from the Childhood Arthritis and Rheumatology Research Alliance registry. Findings demonstrated the relationship between global assessment of disease as reported by patient and by provider was very weak ( $r=0.26$ ). Indeed, teens as a group reported themselves to be significantly sicker than their healthcare providers did ( $p<0.001$ ). There was a significant association between teen's pain ratings and their rating of their disease activity ( $p<0.05$ ). Assessment of the relationship between providers' rating of disease activity and their lab values found no significant correlation between those lab values (normal or abnormal) and the provider's rating of disease activity. Further, teens who did not have labs reported by the provider had a significantly higher discordance score than those who did ( $p<0.01$ ). This is concerning when considering the importance of provider/patient communication, and understanding one another, to determining level of disease activity and management options. This initial study demonstrates a significant need to determine which variables influence the patient/provider communication in order to develop interventions to improve this relationship, promote compliance and reduce negative outcomes in all adolescents with chronic illnesses.

### Biography

Kathleen Kenney-Riley EdD, APRN, BC is a Pediatric Nurse Practitioner with a focus in adolescents with lupus. She has 25 years of clinical and research experience in children with chronic conditions and her research interests are in the area of quality of life, communication with health care providers and methods of improving patient/provider discordance in chronic illnesses. She serves the Editorial Board for the *Pediatric Nursing* and is a voting member of the Childhood Arthritis and Rheumatology Research Alliance (CARRA). She has conducted a secondary data analysis of CARRA data on adolescents with lupus and providers discordance levels.

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